



March 26, 2001

The Honorable John Dingell
U.S. House of Representatives
2322 Rayburn House Office Building
Washington, DC 20515

Dear Representative Dingell:

On behalf of the American Cancer Society and its 28 million supporters, I am writing to thank you and your colleagues – Senators McCain, Kennedy and Edwards and Representative Ganske – for crafting bipartisan legislation H.R. 526, the “Bipartisan Patient Protection Act of 2001,” that meets the needs of cancer patients in managed health care plans. As the largest voluntary health organization dedicated to improving cancer care, we commend you for your continued leadership in assuring strong patient protections.

The American Cancer Society advocates patient protection legislation that provides *all* insured patients with:

- Increased access to clinical trials – assuring that cancer patients who need access to the often life-saving treatments provided in both federally and privately funded or approved high quality, peer-reviewed clinical trials have the same coverage for routine patient care costs as patients receiving standard care.
- Prompt and direct access to medical specialists – patients facing serious or life threatening illnesses, such as cancer, need continuity of care, the option of designating their specialist as their primary care provider, and the ability to have a standing referral to their specialist for ongoing care.
- Strong, independent, and timely external grievance and appeals procedures.

H.R. 526, if enacted into law, would address these issues and remove some of the barriers cancer patients confront in accessing quality medical care.

We would particularly like to thank you for including a strong clinical trials provision that provides access for cancer patients and others with serious and life threatening diseases to both federally and privately sponsored high-quality, peer-reviewed trials. Clinical trials are a critical treatment option for current cancer patients and are also essential in our nation’s efforts to win the War on Cancer. Without clinical trials, new or improved treatments would languish in the laboratory, never reaching the patients who need them. Unfortunately, only three percent of cancer patients currently enroll in clinical trials. Part of the problem is that many health insurers refuse coverage for a patient’s routine care costs if the patient enrolls in a clinical trial – effectively denying access to possibly life saving treatment. Your legislation would remove this financial barrier by requiring health insurance plans to cover the same routine patient care costs that they would cover if the patient were receiving standard therapy.

Improving access to clinical trials has been one of the Society's top priorities for the last several years. Building on a strong bi-partisan Congressional effort, President Clinton issued an Executive Memorandum last year that provided Medicare beneficiaries with serious and life threatening diseases access to the full range of clinical trials. This action was strongly supported by the Society. We appreciate your ongoing leadership, which contributed to the Medicare coverage and will hopefully now lead to ensuring that privately insured patients have access to the same standard of care.

The Society has been a strong advocate for expanding cancer patient access to the full range of clinical trials – including new drug trials approved by the Food & Drug Administration (FDA) and trials investigating improvements in existing, already approved therapies. Expanding access to the full range of trials will help ensure that no one is left behind as we march forward in our fight against cancer. Your provision would provide patients with access to new drug trials approved by the Food & Drug Administration. The Society thanks you for recognizing this critical need as it will help to ensure that cancer patients in privately insured plans have access to new cutting-edge treatments. As we have discussed with your staff, the Society respectfully asks that a technical change to the language be made so patients will have access to both federally funded and approved trials. We know that this was your intent and we are very appreciative of your leadership on this issue.

We would also like to commend you for using the definition of "routine patient care costs" long-supported by ACS and other patient advocacy groups. This definition is also consistent with the Institute of Medicine December 1999 recommendation and current Medicare coverage. By relying on this widely supported definition, your legislation would ensure that patients are not subjected to needless delays in gaining access to the potentially life-saving treatments offered in clinical trials.

The diagnosis of cancer is devastating – patients must not only confront an array of medical decisions, they must cope with the financial and emotional burdens as well. We strongly believe that cancer patients in managed care plans must be assured of access to clinical trials this year and are taking a multi-faceted approach to ensuring that this occurs. As you know, the Society has made it a priority to seek enactment of a broad clinical trials provision as part of a comprehensive Patients' Bill of Rights and it is our hope that legislation such as H.R. 526 – a bill that meets our criteria – will become law in the near future. Once again, we commend you for your leadership and thank you for all of the work you have done to assure the passage of this important legislation that will ensure that cancer patients, irrespective of type of health insurance, will face fewer financial worries as they consider treatment options. If you or your staff have any additional questions, please contact Megan Gordon, Manager of Federal Government Relations (202-661-5716).

Sincerely,



Daniel E. Smith
National Vice President
Federal and State Government Relations

cc: Honorable John McCain
Honorable John Edwards
Honorable Edward Kennedy
Honorable Greg Ganske